



SUPPORTING FAMILY COPING IN PAEDIATRIC INTENSIVE CARE

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ABSTRACT

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AHTI, ILMARI:
Supporting Family Coping in Paediatric Intensive Care

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The objective of this Bachelor's thesis was to explore the nursing methods of and interventions for supporting family coping in paediatric intensive care by means of a literature review. Although a rather large amount of material was obtainable on family experiences in paediatric intensive care settings in general, this Bachelor's thesis specifically focused on the nursing point of view, and the family's interactions with nurses. Through specific focus, I was able to obtain and clearly define arising themes, forming a cohesive line of argument regarding the needs of the family in paediatric intensive care.

The themes were organised under three different categories, which were family centred care, nurse-family interactions, and empowerment. The themes themselves covered the topics of information giving and good communication, empowerment and continuity of care, emotional support and relationship building, and good physical care. Out of the 11 articles analysed in this Bachelor's thesis, at least four articles described each theme.

The articles selected for the analysis in this Bachelor's thesis were all peer-reviewed articles. The articles had all been published in reliable nursing research journals and presented nursing research from various years and decades. The articles were further scrutinised by means of a critical appraisal.

In conclusion, the needs of the family during paediatric intensive care are various, and each family benefits from an individual assessment of their needs. Nursing interventions play a significant role in supporting the family during their time of need and have long-lasting effects on the family and their perception of the support they receive in paediatric intensive care.

Keywords: paediatric intensive care, neonatal intensive care, family centred care, family.

TIIVISTELMÄ

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Opinnäytetyö 24 sivua, liitteet 9 sivua
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Tämän opinnäytetyön tarkoituksena oli tutkia hoitotyön keinoja ja toimintoja perheen tukemiseksi lasten tehohoidossa kirjallisuuskatsauksen kautta. Vaikka paljon tietoa oli saatavilla perheiden kokemuksista lasten tehohoidossa yleensä, tämä opinnäytetyö keskittyi erityisesti sairaanhoidon näkökulmaan sekä perheen vuorovaikutukseen sairaanhoitajien kanssa. Keskittymällä tarkasti rajattuun aiheeseen, tutkimustiedosta ilmenevät teemat olivat helposti määriteltävissä, ja kohesiivinen näkökulma perheen tukemisesta lasten tehohoidossa oli luotavissa.

Ilmenevät teemat olivat jaettavissa kolmeen eri kategoriaan, jotka olivat perhekeskeinen hoitotyö, perheen ja sairaanhoitajan välinen vuorovaikutus, ja voimaannuttaminen. Nämä teemat sisälsivät tiedon antamisen, hyvän kommunikaation, voimaannuttamisen, hoitotyön jatkuvuuden, emotionaalisen tuen, hoitosuhteen luomisen ja hyvän hoidon aihealueet. Tässä kirjallisuuskatsauksessa analysoidusta 11:stä artikkelista vähintään neljä kuvaili jokaista aihealuetta.

Kaikki tämän opinnäytetyön kirjallisuuskatsaukseen valitsemistani artikkeleista olivat vertaisarvioituja. Artikkelit olivat julkaistu luotettavissa hoitotieteellisissä julkaisuissa useina eri vuosina ja vuosikymmeninä. Artikkelien luotettavuutta arvioitiin kriittisen arvion kautta.

Kaiken kaikkiaan perheen tarpeet lasten tehohoidossa ovat monimuotoisia, ja kaikki perheet hyötyvät yksilöllisestä tarpeidensa arvioinnista. Hoitotyön toiminnoilla on merkittävä rooli perheen tukemisessa sitä heidän eniten tarvitessaan, ja niillä on pitkäkestoisia vaikutuksia perheeseen sekä perheen kokemuksiin saamastaan tuesta lasten tehohoidossa.

Avainsanoja: perhekeskeinen hoitotyö, lapsen tehohoito, vastasyntyneen tehohoito, perhe

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1 INTRODUCTION

The child's admission to intensive care is a crisis situation for the family (Scott 1998, 4; Harbaugh, Tomlinson & Kirschbaum 2004, 169) and health care professionals often underestimate the family's need to be present with their sick child and to provide support for the child (Wheeler 2005, 58). The admission becomes a controlling factor for the parents' lives (Hall 2005, 93). The admission also affects the child's siblings due to the fact that the parents have to dedicate a significant amount of their time to the care of their sick child (Holmes 2004, 42). It is therefore important that the intensive care staff recognise the family's situation and utilise means to support the family's coping as well as possible.

This Bachelor's thesis discusses supporting family coping in paediatric intensive care in both neonatal intensive care units and paediatric intensive care units in general, but nursing care performed in maternity wards has not been included in this study. This Bachelor's thesis also focuses specifically on supporting family coping from a nurse's point of view and in nurse-family interaction. My purpose has been to describe research concerning families' interactions with nurses and the support that the family receives from nurses, and my goal to describe how nurses can support family coping in paediatric intensive care based on peer-reviewed research.

Supporting family coping especially during the child's stay in intensive care is little discussed in the Degree Programme in Nursing at Tampere University of Applied Sciences, especially during the basic nursing studies, and there is a great need for additional information on the topic. This Bachelor's thesis can thus be used as a basis for educational material, and Tampere University of Applied Sciences acts as the working life connection for it.

2 THEORETICAL STARTING POINTS

For clarity and to illustrate the key concepts of this thesis, I have described them in detail as the theoretical starting points of this thesis. At the end of this section, I have also included a flowchart demonstrating the interconnectivity of each concept (Picture 1). This interconnectivity is crucial for explaining and justifying the entire research process.

2.1. The Concept of Family Centred Care

Nurses are in an important role in empowering the family and assessing their psychological well-being, therefore making family centred care an important concept to both explore and define. Family centred care in paediatric nursing means that nursing decisions are made in understanding with the family (Kuo, Houtrow, Arango, Kuhlthau, Simmons & Neff 2012, 298). Treatment is planned holistically taking the whole family into consideration, and the whole family is treated instead of only the individual (Shields, Pratt & Hunter 2005, 1318). So far a singular consensus has not been reached on how family centred care should be implemented in practice (Bamm & Rosenbaum 2008; Jolley & Shields 2009 according to Kuo et al. 2012, 298; Trajkovski, Schmied, Vickers & Jackson 2012, 2485).

The meaning of family centred care is both understood and valued, but nurses view supporting and interacting with the family as extremely challenging in paediatric intensive care (Turan, Basbakkal & Özbek 2008, 2858; Trajkovski et al. 2012, 2482). Negative experiences of nurse-family interactions have long-term implications and effects on the parents (Wereszczak, Miles & Holditch-Davis 1997 according to Lam, Spence & Halliday 2007, 20). On the other hand many parents have received enough time and attention as well as information on their child's condition (Haines & Childs 2005, 39).

2.2. The Concept of Empowerment

Empowerment in health care can be understood as a holistic and wholesome approach to supporting the patient's, the patient's relatives', or the professional's mental and psychosocial well-being. Important in empowerment is the individual's perception of their access to the means that best enable them to gain the knowledge, opportunities and support they need to enhance their lives and obtain a necessary sense of meaning. (Spence Laschinger, Gilbert, Smith & Leslie 2010, 5.) This definition of empowerment is applicable to all subjects of the empowerment process.

In relation to parental support, empowerment can further be specifically discerned as a process enabling parents to find the best means of supporting their ill child (Panicker 2013, 211). The Creating Opportunities for Parent Empowerment (COPE) programme has been developed to enhance parental support in paediatric critical illness (Melnik, Albert-Gillis, Fischbeck Feinstein, Crean, Johnson, Fairbanks, Small, Rubenstein, Slota & Corbo-Richert 2004, 597-598; Roets, Rowe-Rowe & Nel 2012, 628). Another similar programme is the Help-Understanding-Guidance (HUG) programme, developed for the purpose of enhancing the parents' comprehension of their child's behaviour in neonatal intensive care units (Kadivar & Mozafarinia 2013, 115).

2.3. Nurse-Family Interactions

In the context of paediatric intensive care, much emphasis in nurse-family interactions can be placed on the development of a relationship that is open and trustworthy. It is important that the nurse understands each family's individuality regarding social, cultural and psychological matters. By asking the family open-ended questions, a therapeutic relationship can be established between the nurse and the family. (Zimmerman & Bauersachs 2012, 52.) A dimension of significant importance in nurse-family interactions is providing the family with the chance to offer their suggestions and opinions regarding the care of their child, as the parents know their child best (Rushton 1990, 72).

2.4. Defining Intensive Care

Intensive care is treatment that is given in intensive care units. The patient's vital functions are constantly observed in intensive care and supported with various devices when needed. The goal in intensive care is to prevent mortal danger and gain time to treat the underlying condition. (Suomen tehohoitoystyksen eettiset ohjeet 1997, 3.) Paediatric intensive care can be divided into neonatal intensive care and general paediatric intensive care.

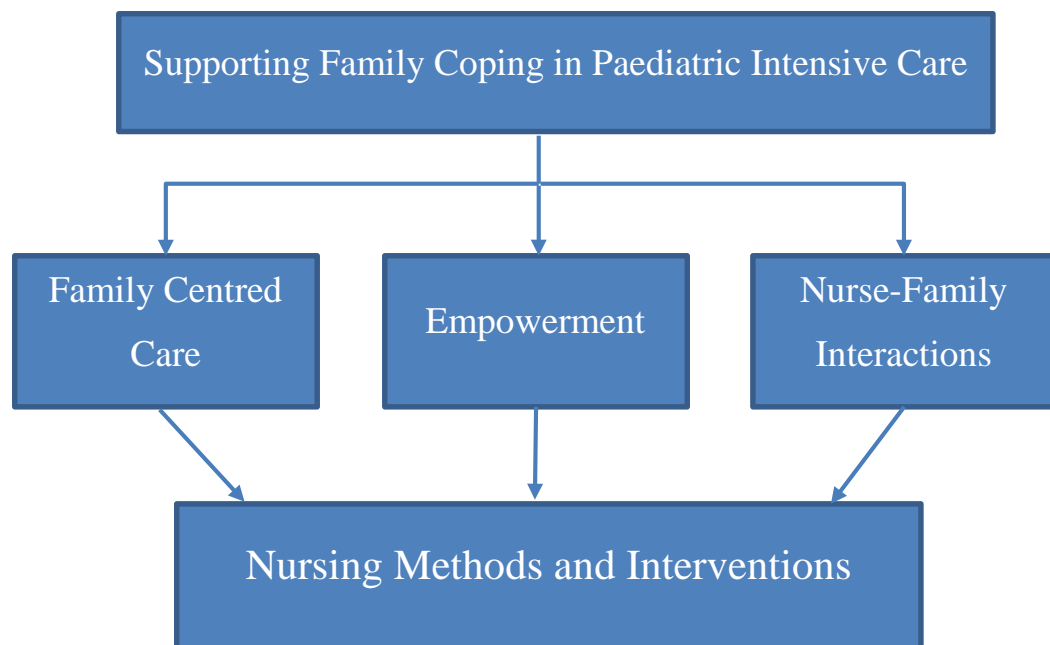
Similarly to adults, paediatric intensive care focuses on seriously ill or injured patients. The patients in paediatric intensive care range from zero to 18 years of age. (The Paediatric Intensive Care Society 2010, 7.) Neonatal intensive care focuses on the provision of care for premature infants, as well as other critically ill neonates (Cleveland 2008, 666-667). The goals of paediatric intensive care are comparable to the goals of general intensive care, with a focus on support for the family and the family's grief and stress (The Paediatric Intensive Care Society 2010, 7-8).

2.5. Family Support in Paediatric Intensive Care

The parents have a great need to be present with their child in the intensive care unit and to receive honest information about their child's condition (Scott 1998, 5). The family's ability to cope with stress during the intensive care period has a significant effect on their relationship with the sick child and the child's development, especially in the case of neonates (Zimmerman & Bauersachs 2012, 50-51). Nurses must know how to support the parents' mental well-being and their role in the child's recovery (Roets et al. 2012, 627).

The parents often want to be present during procedures performed on their child (Miles & Carter 1985, 18). Research has been performed on the parents' presence during their child's resuscitation in intensive care. Many parents identify being separated from their child as a larger stressor than the actual resuscitation (Maxton 2008, 3171). Experience, professionalism and the intuitive mental support given by nurses during resuscitation support the parents' coping (Maxton 2008, 3172).

A significant amount of research has been performed on the various interventions that nurses can utilise to support family coping in paediatric intensive care. Based on his sources, Aldridge (2005, 42-43) divides the interventions that nurses may utilise into four different categories: providing information, supporting the parents' role, building trust, and offering support. Lam et al. (2005, 23) show that the most important methods of supporting the parents in neonatal intensive care are good treatment of the child and enabling parents' participation in the care of the child. The continuity of care and becoming familiar with the nursing staff increase the parents' trust. The nursing staff must show genuine interest in supporting the family. (Haines & Childs 2005, 39-40.)



Picture 1. Flowchart of Key Concepts

3 PURPOSE AND OBJECTIVE

The purpose of this Bachelor's thesis has been to describe research on families' interactions with nurses and the support the family has received from the nurses during their child's stay in paediatric intensive care. My research questions have been:

- How can nurses support family coping in paediatric intensive care?
- What interventions can nurses utilise to support family coping in paediatric intensive care?

The ultimate goal of this thesis has been to create a view of the means nurses can utilise to support family coping in paediatric intensive care, and this also makes it useful for both nursing students and graduate nurses. Nursing students benefit from it because it provides an in-depth theoretical look at the issues concerning family support in paediatric intensive care, and it is also useful for the students' clinical training as well as their paediatric nursing studies. Graduate nurses can utilise this thesis in updating and developing their skills in providing support for the family in paediatric intensive care.

4 METHODOLOGY

A description of the methodological considerations surrounding my work on this Bachelor's thesis is presented in this section. I have primarily utilised the methodological task flow presented by Polit and Beck (2012, 96) in these research processes, seeking to follow the crucial steps for the literature review process presented. I have sought to confirm the validity of the theory on the literature review process described by Polit and Beck (2012) by comparing it to other similar sources discussing both research methodology and its evaluation, such as Schmidt and Brown (2009) and Melnyk and Fineout-Overholt (2011).

4.1. Selection criteria

The key concepts defined in the Theoretical Starting Points section form the theoretical basis based on which I have performed a Boolean meta-search. I have chosen the Cumulative Index to Nursing and Allied Health Literature (CINAHL) as the database for this search. By choosing “family”, “support”, “pediatric” or “paediatric”, and “intensive” as my keywords, I have narrowed down my search results to 39 articles. In order for the search to be thorough, I have also performed similar searches substituting the keyword “family” for “parents” and the keyword “pediatric” for “neonatal”, producing 96 results.

I have further refined my search by rejecting material that is not peer reviewed. As the focus of this thesis lies on nursing methods and interventions, the inclusion criteria for the articles have been a specific focus on the nursing point of view, as well as the capability of answering my research questions. I have not excluded any articles on the basis of their age: Morse (2012, 137) shows that when discussing wider theories or concepts, the age of the material is not a significant concern unless new technology or new methods are the specific subject of study. From the results, I have chosen altogether 11 articles for this literature review. I have sorted the articles by their major findings using a methodological matrix, following the methodology presented by Polit and Beck (2012, 108-110). I have included the methodological matrix as Appendix 1.

4.2. Critical Appraisal

In an effort to increase the validity and the credibility as well as the trustworthiness of this literature review, I have performed a critical appraisal, evaluating the studies I have chosen to analyse as thoroughly as possible. In practical terms, critical appraisal means performing an assessment of the strengths and weaknesses of the studies including their validity, reliability and implications for practice and further research; altogether finding flaws in a field whose inherent nature is to contain flaws, like scientific research (Melnik & Fineout-Overholt 2011, 82-83). Critical appraisal as a technique can be used to assess the quality of any type of research report or article especially in the search of evidence for clinical practice (Melnik & Fineout-Overholt 2011, 73-80; Schmidt & Brown 2009, 317-320), but since the studies I have chosen to analyse are all either quantitative or qualitative research reports not involving case-control or cohort studies or randomised controlled trials, I have utilised guidelines pertaining to these specific types of studies.

Specifically related to the critical assessment of quantitative studies, it is important to assess the statistical significance of the results indicated in the study, as well as the validity and reliability of the study (Melnik & Fineout-Overholt 2011, 83). Other major considerations include the data analysis methods utilised (Melnik & Fineout-Overholt 2011, 99), as well as the methodology of the study as a whole, and the theoretical framework of the study (Polit & Beck 2012, 111-114).

In the critical assessment of qualitative studies, attention is paid to the synthesis of the resultant data into cohesive themes or patterns, creating a logical, interconnected whole (Polit & Beck 2012, 117). This whole might be presented as various lines of argument, as well as a so-called thick description of the phenomenon or phenomena, increasing transferability (Melnik & Fineout-Overholt 2011, 145; Polit & Beck 2012, 116). The validity and reliability likewise present a key consideration in the critical appraisal of these studies, as does the methodology, without which assessing the evidence of the study is difficult (Polit & Beck 2012, 115-118). While an ethical considerations assessment of each article as well as a summary assessment are recommended to be performed by Polit and Beck (2012, 112-117), they have not been included in this critical appraisal, as I have dedicated a full section of this thesis to ethical

considerations (6.1) and a summary assessment of the quality of the articles will play a part in the discussion and limitations sections of this thesis.

I have performed the critical appraisal according to the abbreviated guides to overall critiques of both quantitative and qualitative studies presented by Polit and Beck (2012, 112-117). While according to Polit and Beck (2012, 114-118), these guidelines are not fitting for the needs of a systematic review, they are befitting the purposes of a descriptive literature review such as mine, giving an overall view of the most important aspects of the critical assessment process. They are also not misaligned with the rapid critical appraisal checklists presented by Melnyk and Fineout-Overholt (2011, 513-518), and quite similar to the critical appraisal questions posed by Schmidt and Brown (2009, 318). I have presented the critiquing issues described by Polit and Beck (2012, 112-117) in Appendix 2 and 3.

Having performed the critical appraisal on my chosen studies, I have included the results of this process in two separate evaluation tables. These tables present detailed answers to each of the critiquing issues displayed in Appendix 2 and 3, for both quantitative and qualitative research reports, respectively. I have made these evaluation tables following the visual guidelines of Melnyk and Fineout-Overholt (2011, 520), emphasising clearness and simplicity as also recommended by Melnyk and Fineout-Overholt (2011, 131). These tables are included as Appendix 4 and 5.

4.3. Data Collection and Analysis

The emphasis in the literature review process lies in the analysis of the data collected from the studies chosen for analysis (Polit & Beck 2012, 119). In accordance with this, I have further examined the studies I have critically examined and chosen for this literature review (Appendix 1). I have followed the methodology presented by Polit and Beck (2012, 119-120) by organising the studies into a results matrix (Table 1) presenting the arising commonalities and variations related to nursing methods and interventions in supporting family coping in paediatric intensive care.

In the results matrix, I have identified altogether six categories presenting the most prevalent nursing methods and interventions for providing family support that were

mentioned in the studies I have chosen for analysis. These six categories were: “information giving”, “empowerment”, “continuity of care”, “emotional support”, “relationship building”, and “good physical care”. I have also included a category for mentions of other methods of support less prevalent or befitting.

Table 1. Results Matrix

| Author(s), year | Information Giving | Empowerment | Continuity of Care | Emotional Support | Relationship Building | Good Physical Care | Other themes mentioned |
|--|--------------------|-------------|--------------------|-------------------|-----------------------|--------------------|------------------------------|
| Hall, 2005 | X | | X | X | X | X | Surrogate parent nursing |
| Turan et al., 2008 | X | X | | | | | |
| Roets et al., 2012 | X | X | X | X | | | |
| Trajkovski et al., 2012 | X | X | X | | X | X | |
| Haines & Childs, 2005 | X | X | X | X | X | | |
| Lam et al., 2007 | X | X | X | X | X | | |
| Abib el Halal, Piva, Lago, El Halal, Cabral, Nilson & Garcia, 2013 | X | X | X | X | | | Palliative emotional support |
| Tran et al., 2009 | X | X | | X | | X | |
| Ward, 2001 | X | X | | X | | X | |
| Mundy, 2010 | X | X | | | | | Scales and measurements |
| Able-Boone, Doeckci & Smith 1989 | X | X | X | | | | |

5 RESULTS

The most strongly emerging of the categories of nursing methods and interventions for providing family support in paediatric intensive care were the provision of information for the family and family empowerment. These two categories were outlined and highlighted in each of the analysed articles with few exceptions. The other categories emerging from the articles were correspondent to a various degree, with each category presented in no less than four articles. It is worthy of mention that in this analysis no mentionable discrepancies or disparities between the results analysed from each article have arisen.

While the emergent categories represent the types of support that the results of each of the articles I have analysed had in common, each of the articles presented the types of support in different ways to a varying degree. The differences play the most significant role concerning the methods and means by which the different types of support are provided, not the type of support provided in itself.

A strong commonality regarding the provision of information was that the information should be correct, timely and trustworthy (Able-Boone et al. 1989, 139; Haines & Childs 2005, 38-39; Lam et al. 2007, 22-23; Turan et al. 2008, 2857; Tran et al. 2009, 16; Mundy 2010, 157; Roets et al. 2012, 628; Abib El Halal et al. 2013, 497). Variation regarding the means of providing information existed in the articles: Mundy (2010, 160) explains that information could be provided by telephone, while Haines and Childs (2005, 39), Turan et al. (2007, 2863), Lam et al. (2007, 23), and Roets et al. (2012, 628) describe the provision of written information as an effective method. The rest of the articles I have analysed do not specifically mention a method of providing information, or presumably refer to verbal face-to-face information provision.

I have defined the concept of empowerment in section 2.2 of this Bachelor's thesis. In the light of this definition, the means of empowering the family were also various. The articles mostly described supporting or allowing family involvement in care and teaching methods of caring for the sick child (Haines & Childs 2005, 39; Lam et al. 2007, 23; Tran et al. 2009, 16; Mundy 2010, 160; Trajkovski et al. 2012, 2481) and encouraging frequent visitation to the unit (Ward 2001, 284; Turan et al. 2008, 2865) as

means of empowering the family. The utilisation of COPE guidelines (Roets et al. 2012, 627-629) and the facilitation of parental participation in decisions related to their child's care (Able-Boone et al. 1989, 140; Abib El Halal et al. 2013, 498) were also described as important means of empowerment.

The continuity of care was highlighted in multiple articles as a factor influencing parental coping in a positive way. This type of support was covered by the articles from various different angles and in different ways, nonetheless consistently highlighting the need for the care to be continuous and level. Hall (2005, 92-95) describes the child's transfer to the ICU as a strongly emotional experience for the child's parents in both a negative and a positive way. Roets et al. (2012, 628-629) cover the need for continuity of care from both a managerial perspective and from the perspective of support groups in accordance with COPE guidelines. The continuity of care was further defined as consistency across the whole range of the patient's and the parents' care path (Haines & Childs 2005, 39-40; Trajkovski et al. 2012, 2483-2484; Abib El Halal et al. 2013, 500-501). Nurses were also capable of acting as advocates for the parents in situations of multi-professional interaction, such as between physicians and nurses (Able-Boone et al. 1989, 137-138). Another consideration presented concerns the formulation of a long-term partnership in care with a single care team and how this enhances parental orientation in the intensive care setting (Lam et al. 2007, 24).

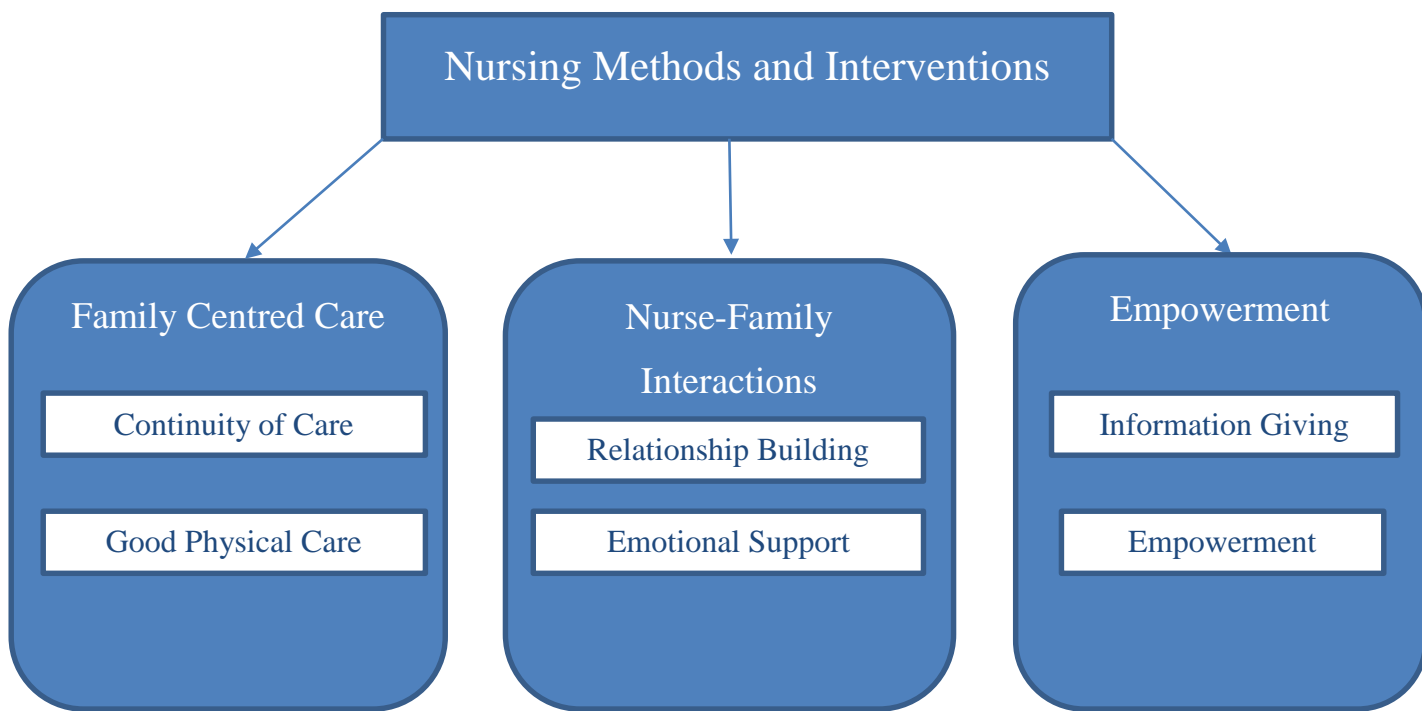
The means of providing emotional support for the family focused on the nurses' capabilities to be present and to provide the parents with a sense of empathetic understanding and support (Hall 2005, 94; Lam et al. 2007, 23-24; Tran et al. 2009, 15; Roets et al. 2012, 627; Abib El Halal et al. 2013, 498). Being present and receptive when the family members needed to share their emotions with the nurse (Ward 2001, 285; Roets et al. 2012, 627) and maintaining an overall open and welcoming atmosphere in the unit (Haines & Childs 2005, 39) as well as showing specific concern for family well-being instead of solely focusing on the infant (Tran et al. 2009, 16) were regarded as significant factors in the provision of emotional support.

In a somewhat interchangeable sense with the concept of continuity of care, the building of a relationship or a partnership in care emerged as its own category in some of the articles. As previously explained, the continuity of care concerns the patient's and the family's whole care path and their relationships with multiple different care teams and

professionals. Differing from that, relationship building in the context of the ICU can more specifically be understood as the relationship that is built between the professional and the family in the day-to-day care of the patient and is based on the unique characteristics of the family (Trajkovski et al. 2012, 2481). This relationship can involve the sharing of experiences and emotions (Hall 2005, 95) as well as partnership in the physical care for the child and decision-making regarding the child's care (Haines & Childs 2005, 39; Lam et al. 2007, 24).

Good physical care emerged as the last significant common category among the articles I have analysed. Good physical care may seem self-evident as a nursing task in the ICU; however, its implications for the parents concerning their emotional well-being were only described by a few of the articles. The effects for the parents from the provision of good physical care for the child were feelings of safety and security (Hall 2005, 94), as well as satisfaction towards the nursing staff (Tran et al. 2009, 16). Scheduling care times and underlining the individual roles of the nurse and the parents in the physical care for the child play a part in the provision of care that is optimal for both the child and the parents (Trajkovski et al. 2012, 2482-2483). Comforting behaviour demonstrated towards the child by the nurses was viewed as important by the parents (Ward 2001, 284-285).

The established emergent categories are not dissimilar to the concepts I have presented in the Theoretical Starting Points section of this Bachelor's thesis. This lends credibility to my results and subsequent line of argument, as earlier theories support their consistency. To highlight this consistency and conceptual flow, I have conceived a flowchart (Picture 2.) that serves as a continuation to the flowchart presented in section 2.5. (Picture 1.)



Picture 2. Flowchart of Results

6 DISCUSSION

The emergent themes obtained through my data analysis process have, in effect, borne a line of argument representing the primary concepts involved in nursing methods of supporting parental coping in paediatric intensive care. Aldridge (2005, 43), Wheeler (2005, 57-59) and Cleveland (2008, 686-688) highlight similar concepts from the viewpoint of the paediatric intensive care units in their literature reviews. This line of argument is represented by the conceptual flowcharts that I have showcased earlier in this Bachelor's thesis, visually demonstrating both the theoretical background of my research process as well as the results obtained through it (Picture 1; Picture 2). By means of placing each emergent theme under a larger category or concept already identified in the theoretical background, I have sought to increase the cohesion of this line of argument.

The research articles I have performed the data analysis on yielded notably similar results containing very few disagreements. While this literature review is not a systematic one and thus its transferability may be considered quite limited, it is noteworthy that studies performed over different years or decades and in a large variety of settings have highlighted such similar themes. The studies I have analysed have furthermore been performed using various methods, traditions and ideologies; in total four of the articles involved qualitative methods, while seven employed quantitative methods. (Appendix 1; Appendix 4-5).

Most strongly the results present the category of empowerment, which in this line of argument is used as a category to represent the overall themes of information giving and family empowerment. The other, less strongly emergent (Table 1) categories of nurse-family interactions and family-centred care are used to cover the themes of relationship building and emotional support, and continuity of care and physical care, respectively.

It is rather evident that when taking into consideration the holistic nature of support the family requires during the intensive care period of the child, the aforementioned categorisation is arbitrary. Models conceived for the provision of family-centred care such as the POPPY model of care (Staniszewska, Brett, Redshaw, Hamilton, Newburn, Jones & Taylor 2012, 247-248) and the COPE guidelines (Melnik et al. 2004, 601-604)

highlight all of the concepts as of equal importance to success. It can thus be said that the concepts rather represent a continuous whole.

Staniszewska et al. (2012, 251) additionally specify that experiences of non-family-centred care carry strong undesirable consequences. Nursing actions carrying negative connotations and thus bringing about negative consequences can be such as deleterious language and demeanour, giving orders to the parents, trivialising their emotional concerns, and following strict regulations (Fenwick, Barclay & Schmied 2001, 53).

While I initially sought out to establish methods of supporting the coping of the whole family unit during the child's intensive care period, little information was obtainable on how the child's siblings or more distant relatives might be supported. It quickly became apparent during the data collection process that a large majority of the literature available on supporting family coping is strongly focused on parental support. Noyes (1998, 141) and Mundy (2010, 162) address the problem of including only the parents in family-centred studies, recommending for further studies to include the siblings or other relatives of the child as well. Mundy (2010, 160) mentions that the parents may not want the sibling or siblings to visit the child during the child's intensive care period, limiting the possible availability of data. Cultural differences may play a part in family members visiting the intensive care unit: family visits may be more restricted in some countries than others (Asai 2010, 63; Soury-Lavergne, Hauchard, Dray, Baillot, Bertholet, Clabault, Jeune, Ledroit, Lelias, Lombardo, Maetens, Meziani, Reignier, Souweine, Tabah, Barrau, Roch & the Société de Réanimation de Langue Française 2011, 1063-1065), further limiting data availability.

Some themes emerged through the data analysis that are related to the overall established themes, but represent a more specific point of view only established in a single article out of the ones I have analysed. These themes were thus given their own category in the results matrix (Table 1). Abib El Halal et al. (2013, 495-502) discuss palliative care in paediatric intensive care in detail. While the overall themes arising from their study correlate well with the other studies, analysing the topic of palliative care and palliation was not the purpose of this thesis, and thus this is mentioned separately and not covered in greater detail. Other mentionable minor theme was surrogate parent nursing as described by Hall (2005, 94), referring to the nurse being especially attentive of the child during the time of the family's distress and inability to

take care of their child, while simultaneously empowering the parents. In addition, Mundy (2010, 162-163) discusses the utilisation of various scales and measurements for assessing parental needs in detail.

Quite importantly, it has been noted that nurses are not reliably capable of predicting the needs of a family, as understandably each family is an entirely discrete unit (Mundy 2010, 163; Trajkovski et al. 2012, 2481). Partially based on this concern as well as for the sake of thoroughness, this literature review comprised of both articles focusing on the family's point of view of their needs, as well as articles describing both these needs and the nurses' implementation of family-centred care based on them.

6.1. Ethical Considerations

While ethical issues should be taken into consideration in all fields of science, nursing as a highly ethically volatile and fragile field comes under specific scrutiny regarding the subject of ethics (Rchaidia, Dierckx de Casterlé, De Blaeser, & Gastmans 2009, 528-529). Ethical issues are regarded to be of key importance especially in studies involving human or animal candidates (Polit & Beck 2012, 150), and in the field of nursing human candidates form the major target group for performing scientific studies.

The literature review performed in this thesis includes no involvement of human subjects in the form of interviews, questionnaires, experiments or other means of research, thus my ethical considerations have been limited to the analysis of the ethical nature of the studies this literature review is based on. I have not needed to ask for permission from an ethical board for my research processes. I have verified the ethical nature of the studies I have analysed by means of critiquing the ethical considerations the researchers mention in their work. Each study subject to analysis in this literature review has a separate section describing the researchers' attainment of permission to conduct their study, and the information given to the research subjects is further detailed.

Polit and Beck (2012, 168) outline how ethics may be taken into consideration in designing studies. When evaluating studies regarding their ethical considerations it is important to estimate, amongst other issues, whether any study participants were

harmful or otherwise affected by the study, whether true informed consent was obtained, and the demographic aspects of the group under study (Polit & Beck 2012, 169-170). While the articles I have chosen for analysis describe their ethical considerations rather shortly and in brief terms, consent obtainment has been specifically taken into consideration in each study, and the demographics of the study group are presented.

6.2. Trustworthiness

Trustworthiness as a term generally refers to the quality of conducted research, often used specifically for qualitative studies, whereas validity and reliability are similar considerations established mainly for quantitative studies (Polit & Beck 2012, 174-175; Farrelly 2013, 149). Trustworthiness encompasses issues strongly relevant to qualitative nursing studies, such as credibility, transferability, verifiability and dependability (Schmidt & Brown 2009, 306-307; Polit & Beck 2012, 175). These issues are also relevant to literature reviews, as the quality of a literature review does not wholly depend on its sources. Whether enough data were collected does, however, represent the key consideration in critiquing literature reviews (Polit & Beck 2012, 123). Literature reviews can also be critiqued for their writing quality as well as the utilisation of appropriate data (Polit & Beck 2012, 122).

By comparing the arising themes and commonalities of each study chosen for analysis to my established theoretical starting points, I have been able to increase the credibility of the consequent descriptive synthesis for which the data analysis serves as a basis, as established by Schmidt and Brown (2009, 308) on the concept of study credibility. Maintaining a clear perception of my research questions and focusing on the established key concepts has thus played an important role throughout this thesis process, in an effort to draw reliable inferences (Polit & Beck 2012, 174).

I have taken into consideration the transferability and the dependability of the literature review process, as recommended by the aforementioned sources. As both the transferability and dependability of a study depend on comparison to an existing theoretical background and other studies and settings (Schmidt & Brown 2009, 308-309; Polit & Beck 2012, 175-180), the theoretical background section as well as the discussion section of this thesis are relevant to these issues.

The reflexivity of this literature review process has been maintained by active supervision and peer critique and evaluations. The key steps to each part of my decision making process are visible, and I have sought to maintain a clear and cohesive flow throughout my writing and research processes. Self-reflection has been a key consideration of mine, and the Bachelor's thesis process has also involved a large amount of group reflexivity. The value of reflexivity in nursing research lies in its reduction of researcher bias (Polit & Beck 2012, 179), thus increasing the verifiability of the study (Schmidt & Brown 2009, 309).

6.3. Limitations

Time and resource constraints have played a major role regarding the limitations of my study. Factors such as performing my literature review alone and in addition to other nursing studies, as well as within a fairly short amount of time, have all certainly played a role in its scope and limited its transferability and generalisability. Performing the literature review alone also increases its risk for bias, decreasing verifiability despite best efforts.

In addition, due to time and resource restrictions, the specific focus of this thesis on the nursing point of view may be considered a limitation, as the issue of supporting family coping certainly includes much more than only the nursing point of view. Being limited to only studies published in the English or Finnish languages also subsequently translates to a limited number of countries being present in the studies I chose for analysis, thus representing a possibly homogeneous sample.

As noted throughout my critical appraisal process (Appendix 4; Appendix 5), the quality of the articles I chose for analysis furthermore adds to the limitations of this study. While the majority of them were of high quality, all research is inherently flawed, and thus the limitations of those articles also affect this study.

6.4. Recommendations

The themes (Picture 2) representing my line of argument translate into practical terms quite well, and are thus suitable to be presented as recommendations for clinical practice. The arising recommendations for clinical practice are also translatable into teaching material for the Degree Programme in Nursing of Tampere University of Applied Sciences in the area of paediatric nursing, as this Bachelor's thesis provides a sound basis of information for nursing skills regarding supporting family coping in paediatric intensive care, when its limitations are taken into consideration.

Based on the articles I have analysed, my study especially places emphasis on the need for nurses to provide holistic care and support for the family during the child's intensive care period. This care involves providing timely, accurate information on the child's condition to the family, empowering and advocating for the family, and guaranteeing the continuity of care, as well as simultaneously providing emotional support for the family as well as good physical care for the child.

Further research should be performed on the needs of the child's siblings and extended family. As I have described in the discussion section, few studies have been performed on this topic, and data collection may be challenging. Furthermore, future studies could seek to detail the consequences of non-family-centred care in more depth, as parental needs are widely discussed, while unmet needs are not.

7 CONCLUSION

The process of writing this Bachelor's thesis has been as much of a learning experience for me as it has been a research project. In fairly equal amounts, I have performed independent writing and research and received timely support and critique from my peers and teachers. From the beginning of the writing process, it has been a special consideration of mine to keep a clear perspective on the goals and the purpose of my study, in an effort to provide the reader with a cohesive, albeit limited view into the topic of family support in paediatric intensive care.

As a highly independent process, all costs related to this Bachelor's thesis process have been covered by me. I have received adequate, detailed feedback from my working life connection throughout the whole process, providing motivation for it. Ultimately, I feel that I have achieved my initial goals and aims well.

While specifically discussing family support in paediatric intensive care, my study demonstrates quite well that providing holistic care for the patient's family is an all-encompassing, timeless topic. As nurses are usually the health care professionals establishing the closest relationship with both the patient and the patient's family and relatives, the provision of holistic care could not be any more essential to nursing practice.

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APPENDICES

Appendix 1. Methodological Matrix

| | | | | | | |
|------------------|---|--|--|--|---|---|
| Author(s), year | Hall, 2005 | Turan et al., 2008 | Roets et al., 2012 | Trajkovski et al., 2012 | Haines & Childs, 2005 | Able-Boone et al., 1989 |
| Country of study | Denmark | Turkey | South Africa | Australia | UK | USA |
| Sample size | 13 participants | 76 participants | 62 participants | 33 participants | 110 participants | 57 participants |
| Methodology | Qualitative; in-depth interviews | Quantitative | Quantitative; structured interviews | Qualitative; semi-structured interviews | Quantitative | Qualitative |
| Major Findings | Child's ICU admission took over parents' time, attention and emotions; mixed experiences of nursing support | A face-to-face introduction and education session statistically lowers parental stress | Family-centred care must be utilised effectively, COPE provides valuable framework | Provision of care to patient and family as a unit; importance of family centred care | Parents' evaluation of the quality of care, development suggestions | Communication, provision of information and parent-staff interactions and involvement of parents in decision making were challenging issues |

| | | | | | |
|---------------------|--|---|---|---|--|
| Author(s), year | Lam et al., 2007 | Abib El Halal et al., 2013 | Tran et al., 2009 | Ward, 2001 | Mundy, 2010 |
| Country of study | Australia | Brazil | USA | Australia | USA |
| Sample size | 62 participants | 13 participants | 62 participants | 52 participants | 60 participants |
| Methodology | Quantitative | Qualitative; semi- structured interviews | Quantitative | Quantitative | Quantitative |
| Major Findings | The quality of care received by the family is not the only factor contributing to stress | Communication, parental participation and compassion highlighted as important factors in support | Perception of support is important to satisfaction with it; areas of nursing support improvement established | Parents regarded reassurance and receiving information as the most important needs. Holistic and continuous family centred care must be implemented by nurses. | Receiving reassurance was found to be important by parents. The needs of parents should be measured by nurses using tools and scales. |

Appendix 2. Quantitative Critical Appraisal Issues (Polit & Beck 2012, 112-114)

| Title | | | |
|--|--|--|---|
| Abstract | | | |
| Introduction | | | |
| Problem Statement: | Hypotheses/Research Questions: | Literature Review: | Theoretical framework: |
| <ul style="list-style-type: none">- Quality- Purposefulness- Significance for nursing- Appropriateness of method for studying problem | <ul style="list-style-type: none">- Appropriate statement & wording- Consistency with theoretical framework | <ul style="list-style-type: none">- Up-to-date, sourcing- Quality of synthesis- Sound basis for new study | <ul style="list-style-type: none">- Key concepts defined- Presence of theoretical framework, justification |
| Method | | | |
| Research Design: | Population & Sample: | Data Collection & Measurement: | Procedures |
| <ul style="list-style-type: none">- Design rigour- Appropriate comparisons- Data collection points- Minimisation of bias and threats to validity | <ul style="list-style-type: none">- Sample description- Sample design/bias- Sample size | <ul style="list-style-type: none">- Operational vs conceptual definitions- Operationalisation of variables- Instruments- Data reliability, validity | <ul style="list-style-type: none">- Intervention, description of it- Data collection reliability |
| Results | | | |
| Data Analysis: | Findings: | | |
| <ul style="list-style-type: none">- Each question/hypothesis addressed- Statistic and analytic methods used- Type I & II errors- Intervention: Intention-to-treat errors- Missing values | <ul style="list-style-type: none">- Statistical significance- Summarisation of findings- Findings reported facilitating meta-analysis, enough information for EBP? | | |
| Discussion | | | |
| Findings' interpretation: | Implications/Recommendations: | | |
| <ul style="list-style-type: none">- Compared to theoretical framework- Causal inferences- Interpretation vs limitations- Generalisability | <ul style="list-style-type: none">- Implications for further research- Implications for clinical practice | | |
| Global Issues | | | |
| Presentation | Researcher Credibility: | | |
| <ul style="list-style-type: none">- Writing quality- Accessibility | <ul style="list-style-type: none">- Qualifications- Experience | | |

Appendix 3. Qualitative Critical Appraisal Issues (Polit & Beck 2012, 115-117)

| Title | | | | |
|--|--|---|--|---|
| Abstract | | | | |
| Introduction | | | | |
| Problem statement: <ul style="list-style-type: none"> - Quality - Purposefulness - Significance for nursing - Match between paradigm/tradition and problem statement | Research Questions /Hypotheses: <ul style="list-style-type: none"> - Appropriate statement & wording - Consistency with philosophy/ideology/tradition | Literature Review: <ul style="list-style-type: none"> - Good summary of existing information - Sound basis for new study | Theoretical Background: <ul style="list-style-type: none"> - Key concepts defined - Concepts/ideology/tradition appropriate for studying problem | |
| Method | | | | |
| Research Design: <ul style="list-style-type: none"> - Tradition aligned with data collection method - Adequate time spent in field/with participants - Design unfolding in field - Number of contacts with participants | Sample & Setting: <ul style="list-style-type: none"> - Sample, setting described - Participant recruitment, site access - Best possible sampling method - Sample size, saturation | Data Collection: <ul style="list-style-type: none"> - Appropriate method used, triangulation - Right questions, observations; recording - Enough in-depth data gathered | Procedures <ul style="list-style-type: none"> - Data collection & recording quality - Bias minimised in data collection - Staff adequately trained | Trustworthiness <ul style="list-style-type: none"> - Sufficient strategies to enhance trustworthiness - Procedure & decision verifiability - Reflexivity - "Thick description" |
| Results | | | | |
| Data Analysis: <ul style="list-style-type: none"> - Data management & analysis quality - Compatibility with tradition, collected data - Was a product yielded - Bias | Findings: <ul style="list-style-type: none"> - Summarisation quality - Themes capturing meaning of data, conceptualisation - Meaningful picture | Theoretical Integration: <ul style="list-style-type: none"> - Themes: continuous whole - Use of figures, maps, models - Themes connected to conceptual framework | | |
| Discussion | | | | |
| Findings Interpretation: <ul style="list-style-type: none"> - Social/Cultural contexts - Interpretation in comparison with former research - Limitations | Implications, Recommendations <ul style="list-style-type: none"> - Implications for further research - Implications for clinical practice | | | |
| Global Issues | | | | |
| Presentation <ul style="list-style-type: none"> - Writing quality - Description of methods, findings, interpretations | Researcher credibility: <ul style="list-style-type: none"> - Qualifications - Experience | | | |

Appendix 4. Quantitative Critical Appraisal Table

| Author(s), year | Turan et al, 2008 | Roets et al, 2012 | Haines & Childs, 2005 | Lam et al, 2007 | Ward, 2001 | Tran et al, 2009 | Mundy, 2010 |
|--|---|---|---|--|--|---|--|
| Title Quality | The title is sufficiently descriptive | Could be more descriptive; only establishes a general theme | Could have been more descriptive of the study's goals | The title is sufficiently descriptive | The title is sufficiently descriptive | Somewhat misaligned with study aims | The title is sufficiently descriptive |
| Abstract Quality | Contains all necessary information | Clear, contains all necessary information | The ultimate goal of the study is not well established | Contains all the necessary information | Contains all the necessary information | Contains all the necessary information | Contains all the necessary information |
| Introduction Problem Statement | Problem is identifiable; theoretical background, purposefulness and significance established; method is appropriate | Easily identifiable study problem; purposefulness and significance of the study established; not the purposefulness of the method | Problem stated well, categorically; purposefulness and significance to nursing are established; method is appropriate | Problem stated well; purposefulness and significance to nursing are established, method is appropriate | No explicit problem statement; purposefulness and significance for nursing established; method appropriate | Clear problem statement; purposefulness, significance for nursing established; method appropriate | Very clear problem statement; purposefulness and significance for nursing established; method is appropriate |
| Hypothesis or Research Question Quality | No explicit statement of research question given | Research questions established; well worded, consistent with theoretical framework | No separate specific statement of the research question given | Appropriately worded research question; consistent with theoretical framework | The aim of the study is appropriately stated, consistent | The aim of the study is stated well; consistent with theoretical framework | The research questions are well stated; consistent with theoretical framework |
| Literature Review Quality | Up-to-date, based on primary sources, good synthesis of background theory; study purposefulness | Up-to-date, based on primary sources; sufficient background, a sound basis for study | Uses old sources, and not very many; very narrow view of theory; does provide a sound basis for the study | Based on good sources, up-to-date; sufficient amount of information, sound basis for study | Wide variety of primary sources; fitting amount of information; a sound basis | Huge amount of up-to-date primary sources; good overall view of theory; a sound basis | Up-to-date, good primary sources; well-encompassing look at theory; a sound basis for new study |
| Theoretical Framework Quality | Key concepts well defined; theoretical framework well established | Key concepts well defined; theoretical framework well established | The relevant key concepts are defined | The relevant key concepts are defined; framework well established | Relevant key concepts defined; framework well established | Relevant key concepts defined; framework established | Relevant key concepts defined; framework established |

| Author(s), year | Turan et al., 2008 | Roets et al., 2012 | Haines & Childs, 2005 | Lam et al., 2007 | Ward, 2001 | Tran et al., 2009 | Mundy, 2010 |
|--|---|--|---|--|--|--|--|
| Method Research Design | Based on formerly developed inventories; few comparisons to earlier studies made; the amount of data collection points is adequate, bias and threats to validity minimised well | Detailed design development and pilot study performance lend credibility and validity; results frequently compared to earlier studies; good number of data collection points | Survey design based on former research with appropriate comparisons present minimising threats to validity; sufficient amount of data collection points present | Questionnaire is based on former research providing validity; some comparisons are made; sufficient amount of data collection points present | Instrument based on former research providing validity; no comparisons made to former studies; sufficient amount of data collection points present | Description of instrument gives rigour; no comparisons to earlier studies; good amount of data collection points | Instrument based on former research giving it validity; comparisons made in its use; a good amount of data collection points present |
| Population and Sample | Sampling described well, no evident bias, representative; sample size is suitable | Sampling described well, no evident bias; only included mothers, no other family members; suitable sample size | Sampling described well; no bias; sample is representative and of a good size | Sampling is described well; no bias; sample is representative, sample size is suitable | Sampling is described well; is representative and suitable sized; no bias | Sampling is described well, is representative; no bias; suitable sample size | Sampling is described well, is representative; no bias; good sample size |
| Data Collection & Measurement | Key concepts operationalised well; sufficient description of instruments and data collection process | Key concepts' operationalisation good; development of the questionnaire is not described well; data collection process described | Key concepts' operationalisation good; development of instrument described; data collection process described | Key concepts' operationalisation justified; instruments backed up by former theory; data collection | Key concepts operationalised well; instrument described well; validity established; data collection not described | Key concepts operationalised well; instrument described well, data collection process valid | Key concepts operationalised well; instrument described, data collection process described |
| Procedures | Intervention is described in detail; it was received by an adequate amount of participants; control group existed | No interventions performed; data were collected by an appropriately trained fieldworker | No interventions performed; data collected by researchers themselves | No interventions performed; data collected by researchers themselves | No interventions performed; data collection process not described | No interventions performed; data collected by researcher | No interventions performed; data collected by multiple people |

| Author(s), year | Turan et al., 2008 | Roets et al., 2012 | Haines & Childs, 2005 | Lam et al., 2010 | Ward, 2001 | Tran et al., 2009 | Mundy, 2010 |
|--|--|--|---|--|---|--|---|
| Findings | Statistical significance is discussed well; findings are summarised with tables & figures; suitably reported for meta-analysis & EBP | No mention of statistical significance; findings are summarised appropriately, reported suitably for meta-analysis & EBP | Statistical significance mentioned; findings are summarised appropriately, reported suitably for meta-analysis & EBP | Statistical significance not specifically mentioned, SD calculated; findings summarised with tables, figures; suitable for meta-analysis EBP | Statistical significance mentioned, SD calculated; findings summarised in tables; suitable for meta-analysis & EBP | Statistical significance addressed, SD calculated; findings summarised in table; suitable for meta-analysis & EBP | Statistical significance addressed, SD analysis; findings summarised, figures; suitable for meta-analysis & EBP |
| Discussion Findings Interpretation | Findings are compared well to theoretical background; causal inferences are discussed; limitations are not in particular mentioned; generalisability isn't discussed | No significant comparison of findings to theoretical background; causal inferences are apparent; limitations are discussed; generalisability is not discussed particularly | Findings are discussed in the light of theoretical background; causal inferences justified well; limitations and generalisability discussed | Great amount of comparison of findings to theoretical background; causal inferences, limitations & generalisability discussed | Findings are discussed in the light of theoretical framework; causal inferences justified, limitations and generalisability discussed | Findings compared in great depth; causal inferences discussed, justified; limitations and generalisability addressed | Findings compared in great depth to theoretical background, causal inferences discussed; limitations and generalisability addressed |
| Implications, Recommendations | No mention of recommendations for further research, clinical practice is discussed | Implications for clinical practice and management is discussed, no mention of further research | Need for further research & implications for clinical practice discussed | Implications for clinical practice discussed, no recommendations for further research | Implications for clinical practice and further research both discussed | Implications for clinical practice and further research both discussed | Implications for clinical practice and further research discussed |
| Global Issues: Presentation | Well written and organised. Lacking a clear research question statement & discussion of limitations; no CONSORT flowchart. Accessibility is debatable | Understandable, cohesive and concise. Accessibility and limitations have been taken well into consideration. | Clearly and well written, the theoretical background and methodology could have been more in-depth; accessible for practicing nurses | Very well written and organised, goes into great detail. The major details are accessible for practicing nurses | Well written and well organised, detail on methodology and data collection processes are lacking; Very accessible for practicing nurses | Well written, very in-depth in nature; organised, cohesive and holistic. Accessible for practicing nurses overall. | An organised study covering all its bases well. Very accessible for practicing nurses with enough visual material. |
| Credibility | Researchers' experience and qualifications establish confidence, as does theoretical framework | Researchers' experience and qualifications establish confidence; the performance of a pilot study adds to the study's credibility | The researchers' qualifications and journal of publication establish a degree of confidence. | The researchers' qualifications and journal of publication establish a degree of confidence. | The researcher's qualifications and journal of publication establish a degree of confidence | The researcher's qualifications and journal of publication establish a degree of confidence | The research is a qualified, experienced researcher writing for a well-established journal. |

Appendix 5. Qualitative Critical Appraisal Table

| Author(s), year | Hall, 2005 | Trajkovski et al, 2012 | Abib El Halal et al, 2013 | Able-Boone et al, 1989 |
|--|--|---|--|---|
| Title Quality | High quality, sufficiently descriptive | A clarification on what aspect of family centred care is under study would have benefitted the title | Doesn't reflect the study's specific aims very well | Reflects the purposes of the study well |
| Abstract Quality | Concise, well-written, no details about study population | Well written, well organised, easily understandable, contains all the necessary information | High quality, sufficiently descriptive, including all relevant issues | Very short, not very detailed nor descriptive abstract; no information about methodology |
| Introduction Problem Statement | Problem is stated well, purposefulness and significance for nursing is established; method is valid for studying problem | The problem is stated unambiguously, purposefulness and significance for nursing are apparent, methodology is matched with problem | Not stated unambiguously, main idea comes through in the introduction; study's purpose and significance established; methodology is matched well with problem | Not very easily identifiable; purposefulness and significance established by theoretical framework and arguments therein |
| Research Questions | Explicit, well-written statement of study aims, consistent with study's ideology | The study aims are stated explicitly, research question is very consistent with established ideology | The aims of the study are stated explicitly; are consistent with study's established ideology | Well understandable, clear study aims; consistent with the overall framework of the study |
| Literature Review Quality | In-depth summary on the study problem; provides a sound basis for the study | Vast amount of in-depth information present, study's relevancy established | A good in-depth look at the issue; basis for study is established by literature review | Only covers the theoretical background in short terms; based on few sources; does provide a sound basis for new research |
| Conceptual Underpinnings | The key concepts for the study are described well, as is the study paradigm | The key concepts are detailed well, the theory of family centred care detailed at great length | The key concepts are covered adequately; no explicit statement of ideology | Theory on parental involvement in decision making not detailed; statement of study tradition present |
| Methodology Research Design & Tradition | The research tradition and the data collection method were aligned; enough time spent on the field, and enough contacts with participants | Research tradition and data collection method aligned well; suitable time was spent with participants and on the field, inductive data analysis process is presented | Research tradition and data collection method aligned; amount of time spent with each subject was appropriate; adequate amount of contact with each subject | Tradition and data collection method are aligned; no mention of time spent in study; new categories emerged as data were collected; adequate time spent with study participants |
| Sample & Setting | Study population, setting and recruitment all described well; a small convenience sample was used, no mention of saturation achievement | Sampling, setting and recruitment appropriate and well described; sample only covers nurses working in the study's unit; no mention of saturation | Study population is described well; the sampling method is in line with study tradition; the sample size is very, very small | Sample is described well, setting is not; recruitment was appropriate; sampling methodology not justified well; sample size quite appropriate |
| Data Collection | The data gathering method and the interview questions and observations are well detailed, appropriate amount of data gathered | Data gathering and analysis were rigorous, triangulation utilised; study questions not recorded; suitable amount of data present | Data gathering methods were appropriate and well-described, some questions and observations recorded; suitable amount of data present | Data gathering methods quite valid and appropriate; questions and observations adequately recorded; suitable amount of data gathered |
| Procedures | The data collection is recorded appropriately, risk of bias arise from researcher herself acting as 'instrument' for study | Data collection has been suitably recorded; rigour minimises the risk of bias, but this is not described in detail | Data collection recorded well; bias minimised by researchers not involved in child's treatment and multiple researchers for different study phases | Data collection described appropriately; bias minimised by multiple researchers performing interviews, no mention of other methods |
| Trustworthiness | Trustworthiness, validity and generalisability discussed in their own section; limitations are well acknowledged, a good amount of description of study procedures and reflexivity present | Rigour and extensive theoretical framework increase trustworthiness; validity could have been discussed more; reflexivity is not very apparent; transferability is established by "thick description" | No mention of strategies to enhance trustworthiness; researchers' decision making does not come through clearly, reflexivity and transferability not very apparent | No mention of specific strategies to enhance trustworthiness, the study process is very transparent; researcher reflexivity comes through quite well, there is an in-depth thick description of results for transferability |

| Author(s), year | Hall, 2005 | Trajkovski et al., 2012 | Abib El Halal et al., 2013 | Able-Boone et al., 1989 |
|--|--|--|---|---|
| Results Data Analysis | The data analysis is described sufficiently; data analysis strategy is compatible with methodology, emergent themes arose, the possibility of bias is an acknowledged limitation | Data management & analysis described in great detail; data analysis is compatible with methodology; emergent themes present; rigour minimises presence of bias | Data management & analysis described sufficiently; strategy compatible with methodology; emergent themes present; bias minimised sufficiently | Data management & analysis described well; strategy definitely compatible with methodology; thematic categories yielded by study; transparency minimised study bias well |
| Findings | Findings summarised well with excerpts and arguments, themes are conceptualised well, a holistic view of the phenomenon | Great summarisation of findings, very detailed, good use of excerpts; themes are turned into concepts well, meaningful picture established | Suitable amount of excerpts and arguments summarising findings; themes are conceptualised well; meaningful whole presented | Arguments and excerpts represent a good summary; established themes describe obtained data well; a meaningful picture of presented of the phenomenon |
| Theoretical Integration | Themes represent a continuous whole, and are connected to theoretical frame-work; no models or figures used | Themes represent a holistic look at family centred care; connected to theoretical framework; no models or figures | Themes represent a whole, but not all emergent themes have been described; no pictures, maps or models used | A continuous whole is represented well by the themes; a table is used to summarise themes; emergent themes are connected to the short theoretical background |
| Discussion Findings Interpretation | The findings' cultural context is discussed; findings are discussed well in context of theoretical frame-work. Consistent with limitations. | No discussion of the social/cultural context; findings interpreted well with theoretical frame-work; consistent with limitations established | The cultural concept is discussed but not to a great extent; major findings discussed well in context of theoretical framework; findings believable in light of limitations | No discussion of the social/cultural context; findings interpreted in the context of theoretical framework; the findings are consistent with the established limitations |
| Implications, Recommendations | Implications for both clinical practice and further research are discussed | Clinical relevance discussed, no discussion of implications for further research | Implications for both clinical practice and further research are discussed | Implications for both clinical practice and further research are discussed |
| Global Issues Presentation | The study is well-written and well organised with sufficient detail; would have benefited from the usage of maps or models | Well written and very detailed, would have benefitted from a descriptive summary or chart; more details on data collection process would've been good | Well written and organised, does not contain all the details researchers obtained; study would have benefitted from figures or models and discussion of trust-worthiness | Well written and organised and easy to follow; does not go into enough detail in its theoretical framework, but methodology and results shine through; arguments posed are believable |
| Credibility | The researcher's experience and qualifications, transparency and theoretical framework establish credibility well | The researchers are qualified and experienced, which establishes confidence, as does the journal of publication | The researchers' qualifications and experience and the presence of a large multi-professional team raise confidence in the reader | The researchers' credentials are not mentioned. The peer-reviewed journal of publication arises confidence, as does the study method based on strong former research |